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The Relationships among Hope, Pain, Psychological Distress, and Spiritual Well-Being in Oncology Outpatients

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Abstract

Objective: Limited research in Taiwan and Europe suggest that hope is inversely correlated with certain dimensions of the pain experience. However, the relationship between hope and pain among oncology outpatients in the United States has not been evaluated. The aims of this study were to investigate the relationship between hope and cancer pain, after accounting for key psychological, demographic, and clinical characteristics.
Design: We enrolled a convenience sample of 78 patients who were receiving concurrent oncologic and symptom-focused care in a comprehensive cancer center. Patient demographic and clinical information was obtained from patient report and medical record review. Patients completed the Herth Hope Index, the Brief Pain Inventory, the Hospital Anxiety and Depression Scale, and the Steinhauser Spiritual Concern Probe.
Results: Levels of hope were not associated with age, gender, or the presence of metastatic disease. Herth Hope Index scores were negatively correlated with average pain intensity ($p = 0.02$), worst pain intensity ($p < 0.01$), pain interference with function ($p < 0.05$), anxiety ($p < 0.01$), and depression ($p < 0.01$), and were positively correlated with spiritual well-being scores ($p < 0.01$). However, after controlling for depression and spiritual well-being with regression analysis, the relationship between pain intensity and hope was no longer significant.
Conclusions: While an association exists between the patients' experience of pain and levels of hope in this study, adjustment for depression and spiritual well being eliminates the relationship initially observed. Although the causal relationships have yet to be determined, in our study hope had a stronger connection to psycho-spiritual factors, than to pain experiences or severity.

Introduction

Maintaining hope in the face of serious illness has long been a goal of patients, families, and clinicians. However, relatively little is known about the factors that sustain hope.[1,2] Even so, hope is a key clinical and perhaps therapeutic variable, affecting cancer patients' adjustment and coping skills, overall well-being, immune function, and quality of life.[3–10] Conversely, lack of hope and hopelessness is associated with physical illness, depression, and wish to hasten death.[11,12] Therefore, developing greater understanding of the demographic and clinical factors that might be associated with or influence a patient's degree of hope could lead to strategies to identify patients at higher risk for hopelessness or factors that could be targeted by interventions to improve hope and coping with cancer.

Defining and operationalizing hope is a complex endeavor as the term has many different interpretations, meanings, and usages. Qualitative investigations of hope within nursing literature have helped describe and define the concept in terms of its sources, attributes, and goals. According to the conceptual model developed by Dufault and Martocchio, hope is a "*multidimensional* dynamic life force characterized by a *confident* yet *uncertain* expectation of achieving a future good which, to the hoping person, is realistically possible and *personally significant*." Furthermore, hope is described as a "complex of many thoughts, feelings, and actions that change with time." Based on extensive research, Dufault and Martocchio conceptualized hope as composed of two spheres, "generalized hope" and "particularized hope," each consisting of six shared dimensions: cognitive, temporal, affective, behavioral, affiliative, and contextual.[13]

As described in reviews by Butt[14] and by Chi,[15] a number of studies have investigated the role of hope in different populations of cancer patients using qualitative and/or quantitative methods. Various instruments have been used to measure hope, most common of which is the Hearth Hope Scale and its more concise counterpart, the Herth Hope Index (HHI). Of the

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studies that have quantitatively assessed the relationship between hope and cancer pain, findings have varied.[16–21] Some research has evidenced direct negative correlations between pain severity and hope.[16,18,22] Other studies, however, show no significant direct correlations between hope scores and pain intensity or duration.[17,20] For example, a cross-sectional study of hospitalized cancer patients in Norway found HHI scores correlated negatively with several of the interference items on the Brief Pain Inventory (BPI), but not with pain severity per se.[20] A study investigating the association between pain and hope levels in hospitalized Taiwanese cancer patients concluded that HHI scores did not differ between patients with and without cancer pain. However, among those patients with pain, hope levels correlated with patients' beliefs about their pain symptoms rather than the pain itself (i.e., pain duration, intensity, and relief), suggesting that cognitive and emotional processing may mediate the relationship between pain and hope.[17]

To our knowledge, none of the studies focused on hope and pain levels to date have included metrics of both psychological and spiritual well-being. According to Chochinov and others, spirituality can play a significant role in maintaining hope, and it has been recognized by the Institute of Medicine as an important aspect of supportive care at end of life.[22–25] Research has also provided empirical support for the hypothesis that spiritual well-being might help to bolster psychological functioning and adjustment to illness.[15,26–28]

Because the prior literature has delivered inconsistent results and primarily focused on inpatients, the goal of this study was to examine the relationship between pain and hope among oncologic outpatients, while also controlling for psycho-spiritual factors and other potentially significant clinical and demographic variables. It was also important to evaluate the relationship between hope and pain among patients in the US, because prior published studies were set in Europe and Asia.

Methods

Patients and setting

Patients ($n=78$) were recruited from the Symptom Management Service (SMS), an oncologic outpatient consultation service at the University of California, San Francisco (UCSF) Helen Diller Family Comprehensive Cancer Center. Patients were included if they were able to complete surveys in English, able to provide informed consent, were >18 years of age, and had a diagnosis of cancer. Patients with diagnoses of dementia or psychosis were excluded. Institutional Review Board approval was received before data collection began. Medical records were reviewed to confirm cancer diagnoses and to investigate the presence of metastatic disease.

Study instruments

Patients were recruited in the SMS clinic waiting area. After obtaining written informed consent, patients completed a demographic questionnaire, the HHI, BPI, Hospital Anxiety and Depression Scale (HADS), and Steinhauser Spiritual Concern Probe (SSCP). We selected these measures based on the frequency of their use in the literature, ease of administration, and construct validity and internal consistency ratings.

The HHI is a 12-item score questionnaire that uses a 4-point Likert scale to assess level of hope.[29] The HHI, developed in the oncology setting to operationalize and quantify hope for research and clinical purposes, is based upon Dufault and Martocchio's conceptual framework of hope. Through psychometric validation studies using factor analysis, Herth successfully identified three subscales—temporality and future, positive readiness and expectancy, and interconnectedness. These three subscales correspond to the cognitive-temporal, affective-behavioral, and affiliative-contextual dimensions elucidated in the Dufault and Martocchio model.[13] Total HHI score ranges from 12 to 48 with higher scores corresponding to higher levels of hope. Overall scores provide a validated and reliable measure of global hope for cancer patients with an alpha coefficient of 0.97 and a reliability coefficient of 0.91.[29]

The BPI is a valid and reliable scale for assessing both pain intensity and pain interference with daily activities, using an 11-item questionnaire.[30] The first part consists of four questions that addresses pain severity (where zero refers to "no pain" and 10 to pain as "bad as you can imagine"), whereas the second part asks about pain interference with seven aspects of function (where zero refers to "does not interfere" and 10 to "completely interferes"). The questionnaire in our study was based on pain experienced over the past week, as in the long version of the BPI.

The HADS is a tool designed for physically ill patients to measure anxiety and depression. It avoids reliance on the physical symptoms of psychiatric disease that result from the physical illness itself. This 14-item scale has been widely validated for use with cancer patients.[31]

The SSCP uses a 5-point Likert scale to evaluate a patient's sense of spiritual well-being by asking to what degree the patient feels "at peace." Higher scores signify greater spiritual well-being. It has been validated as a screen for spiritual distress, associated with both religious and meaning-making elements of spirituality.[32]

Statistical analysis

Data analyses were conducted using SPSS for Mac Release 20.0.0 (SPSS, Inc., Chicago, IL). Descriptive statistics were generated to assess the sample in terms of demographics and clinical characteristics. Pearson's product moment correlations between levels of hope and cancer pain intensity, anxiety, depression, spiritual well-being, and demographic variables were determined. Based on the patient sample size, the study achieved power to detect a moderate correlation ($r=0.25$–0.30) at 80% power.[33] All tests were two-tailed with an alpha $=0.05$.

A multivariate linear regression model was constructed to evaluate the effects of potential confounders that might systematically bias the association found between pain intensity and HHI scores in the univariate analysis. Each of the variables of interest had skewness values less than twice their standard errors, consistent with normal distributions. Hence, we proceeded with parametric analyses. The dependent variable in the model was HHI score. The predictors were selected by including demographic and clinical variables deemed important a priori (i.e., age, gender, education, marital status, religion, and the presence of metastatic disease), then clinical predictor variables most highly correlated in the

univariate correlational analyses (HADS scores, SSCP score, worst pain in the last week, and pain interference with mood and function). Multicollinearity was assessed for these variables with the use of correlation matrices and variance inflation factors, as well as the possibility of interaction between pain variables included in the model and depression scores. The final model for the sake of parsimony retained only those factors found to be statistically significant predictors with a p value of < 0.05. An overall goodness of fit of the regression model was calculated.

Results

Patient enrollment

From a convenience sample of SMS patients, 95 patients were approached to participate and 78 (82%) agreed to participate, provided written informed consent, and completed the questionnaires. Eleven patients (12%) were not enrolled in the study because they either did not meet the inclusion criteria ($n = 4$) or declined to participate ($n = 7$). In addition, six surveys (6%) were not included in the sample because the questionnaire was inadequately completed, whether due to inadvertent omission of key survey elements ($n = 2$), patients' time constraints ($n = 2$), or the patients' feeling "too ill" to continue ($n = 2$). Of the seven patients (7%) who declined to participate, four did so out of concerns about privacy and/or reluctance to participate in research more generally. The other three cited feeling "too ill" or "too stressed-out."

Table 1. Descriptive Data for the Sample

Characteristic	n	%
Gender		
Women	50	64.10%
Men	28	35.90%
Education		
Middle school	1	1.28%
High school	12	15.38%
College	39	50.00%
Graduate degree	26	33.33%
Marital Status		
Single	37	47.44%
Married/partnered	41	52.56%
Religion		
Buddhist	9	11.54%
Christian	29	37.18%
Jewish	11	14.10%
Hindu	0	0%
Muslim	0	0%
None	23	29.49%
Other	6	7.69%
Primary Cancer		
Brain	3	3.85%
Breast	22	28.21%
Gastrointestinal	3	3.85%
Gynecologic	13	16.67%
Head/Neck	8	10.26%
Hematologic	2	2.56%
Lung	5	6.41%
Other	5	6.41%
Prostate	12	15.38%
Urological	5	6.41%
Age		
age < 40	7	8.97%
age 40-64	46	58.97%
age 65 +	25	32.05%
Metastatic Disease		
No	26	33.33%
Yes	52	66.67%
Ever Had Pain Related to Present Illness?		
No	10	12.82%
Yes	68	87.18%

Demographic characteristics

The sample consisted of 64% women and 36% men with a mean age of 57.6 years (standard deviation [SD] = 13.0) (Table 1). Nearly 60% of the sample patients were between the ages of 40 and 64; 32% were ≥ 65 years of age and 9% were < 40. Representative of the SMS patient population, 69.2% of patients self-identified as white, 10.3% African American, and 7.7% Asian. The sample patients were highly educated with 83% having completed college or graduate school. Over half (52.6%) of the sample patients were married or partnered. In terms of religious affiliation, 37.2% identified as Christian, 14.1% as Jewish, 11.5% as Buddhist, 7.7% as other (usually denoted as "spiritual" by patients), and 29.5% as "none."

Clinical characteristics

The three most common cancer diagnoses were breast (28.2%), gynecologic (16.7%), and prostate (15.4%), which is reflective of the proportions within the SMS at large. Two-thirds of the patients (66.7%) had metastatic disease.

The majority (87.2%) of the sample patients had pain due to the cancer or its treatment. The mean pain score among those with pain over the past week was 3.4 (SD = 2.5) (Table 2). The mean level of pain at the time of the survey and at its worst was 2.8 (SD = 2.7) and 4.7 (SD = 3.4), respectively. The mean total HHI score was 38.2 (SD = 5.09). The mean level of spiritual well-being was 3.3 (SD = 1.01).

Patients had a mean score of 14.3 on the HADS (SD = 6.3) with 6.6 on the depression subscale (SD = 3.5) and 7.7 on the anxiety subscale (SD = 3.8). Nearly 50% of patients had scores in the normal range on the HADS anxiety subscale, 28% had borderline scores, and 23% had abnormal scores (Table 3). On the HADS depression subscale, 56% of patients had levels in the normal range, 31% of patients scored in the borderline range, and 12% in the abnormal range.

Associations between levels of hope and demographics, clinical characteristics, symptoms, and spiritual well-being scores

Among the demographic variables (i.e., age, gender, ethnicity, marital status, religion, and education level), only education level showed a significant univariate correlation with HHI scores (Table 3). Higher education level was associated with higher HHI scores ($r = 0.26$, $p = 0.02$). HHI was not associated with the presence of metastatic disease.

Among pain variables, total HHI scores were negatively correlated with ratings of worst pain over the last week ($r = -0.28$, $p = 0.01$), average pain over the last week ($r = -0.27$, $p = 0.01$), and with all BPI pain interference items except level

Table 2. Scores for Pain, Hope, Depression, Anxiety, and Spiritual Well-Being

	N	*Mean*	*SD*	*Min*	*Max*
BPI					
Average Pain Over the Last Week	78	3.38	2.45	0	9
Current Level of Pain	78	2.79	2.68	0	9
Worst Pain in Last Week	78	4.67	3.35	0	10
HHI	78	38.22	5.09	28	48
SSCP	77	3.32	1.01	1	5
HADS (Total Score)	77	14.28	6.33	2	31
HADS - Depression Subscale*	77	7.66	3.84	0	15
HADS - Anxiety Subscale*	77	6.62	3.5	1	16

*HADS subscale scores between 0 and 7 is "normal," 8–10 is "borderline abnormal," and 11–21 is "abnormal."

of interference with relationships: work ($r = -0.23$, $p = 0.04$), sleep ($r = -0.25$, $p = 0.03$), enjoyment ($r = -0.25$, $p = 0.02$), ability to walk ($r = -0.28$, $p = 0.01$), mood ($r = -0.33$, $p = 0.004$), and general function ($r = -0.28$, $p = 0.01$).

Depression and anxiety each were negatively correlated and spiritual well-being positively correlated with total HHI scores with correlations of -0.56, -0.48, and 0.52, respectively, each with p values of < 0.001.

The multivariate linear regression models constructed to predict HHI score (Table 4) indicate that spiritual well-being scores and depression scores were statistically significant predictors of hope. In the final model (Table 4B) SSCP score had a β coefficient of 1.55 ($p < 0.01$), and HADS depression score had a β coefficient of -0.63 ($p < 0.01$). The overall adjusted R^2 for the model was 0.38, $p < 0.001$. Pain intensity, BPI functional interference scores, gender, education, marital status, religious affiliation, metastatic disease, and HADS anxiety scores though initially included in the model were ultimately not statistically significant, and hence not retained in the final regression model. Of note, there were no significant multiplicative interactions found between pain severity scores and HADS depression scores.

Table 3. Univariate Correlations with HHI

	r	p-*value**	n
Demographics			
Married	0.14	0.24	78
Higher Educational Level	0.26	**0.02**	78
Male Gender	0.06	0.60	78
Age	0.09	0.42	78
Clinical Characteristics			
Metastatic Cancer	0.10	0.38	78
Presence of pain due to cancer	−0.01	0.91	78
Worst pain over last 1 week	−0.28	**0.01**	78
Average pain over last 1 week	−0.27	**0.01**	78
Pain right now	−0.2	0.08	78
Pain Interference With Function			
Work	−0.23	**0.04**	78
Relationships	−0.20	0.08	78
Sleep	−0.25	**0.03**	78
Enjoyment	−0.25	**0.02**	78
Ability to Walk	−0.28	**0.01**	78
Mood	−0.33	**<0.01**	77
General Function	−0.28	**0.01**	78
HADS (Total Score)	−0.62	**<0.01**	78
Depression subscale	−0.56	**<0.01**	77
Anxiety subscale	−0.48	**<0.01**	77
SSCP	0.52	**<0.01**	77

*Bold indicates $p < 0.05$.

Table 4A. Initial Multivariate Linear Regression Model for HHI Score

Regression variables	*ß (SE)*	p-*value*
Age	−0.05 (0.04)	0.26
Gender (0 = female; 1 = male)	−1.29 (1.04)	0.22
Marital status (0 = single; 1 = married)	1.68 (1.00)	0.10
Metastatic cancer (0 = no; 1 = yes)	1.02 (1.03)	0.33
Any religious affiliation (0 = no; 1 = yes)	−0.08 (1.10)	0.95
Education (0-less than college; 1 = at least college degree)	2.48 (1.43)	0.09
Pain (worst in last week)	−0.09 (0.23)	0.69
SSCP	1.46 (0.62)	0.02
HADS- Depression Score	−0.55 (0.16)	<0.01
HADS- Anxiety Score	−0.23 (0.19)	0.24
Pain interference w/ general function	−0.01 (0.26)	0.97
Pain interference w/ mood	0.16 (0.27)	0.57

$R = 0.70$, $R^2 = 0.49$; adj $R^2 = 0.40$.
$F(12,62) = 5.03$; $p < 0.001$.

Table 4B. Final Multivariate Linear Regression Model for HHI Score

	ß (SE)	p-*value*
SSCP	1.55 (0.53)	<0.01
HADS- Depression Score	−0.63 (0.15)	<0.01

$R = 0.63$, $R^2 = 0.39$; adj $R^2 = 0.38$.
$F(2,73) = 23.72$; $p < 0.001$.

Discussion

This study is unique in that it is one of the few to examine the relationship between hope and pain among cancer outpatients in the United States, and to our knowledge, the only one of these to also consider spirituality. We also utilized multivariate linear regression to assess confounding by various demographic and clinical factors. We found that symptoms of depression and spiritual well-being independently predicted levels of hope, eclipsing the univariate correlation between pain severity and hope initially observed.

The pain and levels of hope found in this study are similar to those found in prior literature, which suggests some degree of generalizability. The mean hope level found in this study's patient population was in the upper range but comparable to those found in other studies with HHI scores ranging between 32.5 and 39.[17–20,34–36] The average pain score in the study population was also well within the range found in other

related studies.[17,21,34,35] Our results expand on the existing research in this field by incorporating additional psychospiritual factors into the assessment of the relationship between pain and hope. These findings clarify the suggestion in recent literature that hope is related most closely to psychosocial elements of the pain experience, rather than pain intensity.[20,21]

Among its limitations, our study was cross-sectional. To further explore the causal links between hope, pain, and psychospiritual factors, a longitudinal study would be ideal. Additionally, this study was limited by the recruitment pool available within the study site, and the demographics of our population under-represented certain minority groups. This study did not control for certain cancer-related symptoms experienced by patients, such as nausea, dry mouth, insomnia, anorexia, weight loss, and fatigue, which are other potential confounders of the relationship between pain and hope. Also, we did not control for patients' beliefs regarding their prognoses, although we did record diagnoses and were able to control for the presence of metastases. A final limitation of this study is that we minimized the time burden on patients by using a single-item probe of spiritual well-being. To further explore the complex dimensions of spiritual beliefs would require more extensive quantitative measures than the SSCP or qualitative methods.

The lack of congruency between the univariate correlations and multivariate modeling in this study highlights the importance of measuring and accounting for factors in multiple domains simultaneously. Based on our findings, we deduce that depressive symptoms and spiritual well-being mediate patients' experiences of pain, influencing their beliefs about, attitudes toward, and interpretations of pain. As the experience of pain is a subjective phenomenon, the affective and cognitive filtering of pain likely matters more than measureable nociceptive and neuropathic intensity in relationship to levels of hope.[37,38]

This study buttresses the notion forwarded by other researchers that patients may maintain a sense of hope even while cancer pain and other symptoms progress, as a function of cognitive-affective and psycho-spiritual resources and resiliency.[39] On a practical note, this study suggests that when confronted with a patient who seems to have "lost hope," the physician should look beyond pain measures and explore psychological adjustment and spiritual concerns. Furthermore, interventions to sustain or promote hope among cancer patients with pain should carefully consider the role of mental and spiritual health and well-being.

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Author Disclosure Statement

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